The provision of specialist psychosocial support for people with visible differences: A European survey

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Brief research report

The provision of specialist psychosocial support for people with visible differences: A European survey

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ABSTRACT

A substantial body of research has demonstrated the challenges commonly facing people with visible differences (disfigurements) and explored the potential benefits offered by specialist psychosocial support and intervention for those who are negatively affected. However, little is known about the availability of such support in Europe for people whose appearance is in any way different to 'the norm'. This survey of 116 psychosocial specialists from 15 European countries, working with a range of patient groups, has shown a tendency for specialists to prioritise Cognitive-behavioural-based approaches, amongst a wide range of other approaches and interventional techniques. It indicates variations in the availability of support, and a perceived need for improved access to interventions, additional training, and greater awareness of the psychosocial issues associated with visible differences.

1. Introduction

An estimated 10.2 million people in Europe have a visible difference (disfigurement) (M. Persson, personal communication, 27th July 2017), defined as looking different from what most would consider 'the norm' (Rumsey & Harcourt, 2012). This includes congenital (e.g., cleft lip/palate) and acquired conditions (e.g., psoriasis), or the consequences of trauma (e.g., burns) or biomedical treatments (e.g., surgical scarring). Irrespective of the type or aetiology of visible difference, challenges commonly experienced by those affected include dealing with the reactions of other people (including staring and unsolicited questions) and managing any negative impact on self-esteem and quality of life, in addition to social anxiety, avoidance behaviours, and depressive symptoms. These challenges have been documented by researchers (e.g., Feragen, 2012; Martin, Byrnes, McGarry, Rea, & Wood, 2017) and in personal accounts (e.g., Connolly, 2009; Partridge, 2006). Whilst many manage without needing high level support, others may benefit from interventions delivered by psychosocial specialists in this field (see Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014).

Funding from the European Cooperation of Science and Technology (COST) enabled a network for researchers and practitioners interested in appearance and body image (www.appearancematters.eu). Within this, we established a task group focussing on psychosocial interventions for visible differences, aiming to share expertise, promote intervention development, and identify best practice. This required a detailed understanding of available research evidence and service provision.

Systematic reviews conclude that cognitive behavioural therapy (CBT) and social interaction skills training dominate this field, and call for a broader repertoire of interventions to meet clients' needs

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(see Bessell & Moss, 2007; Jenkinson, Williamson, Byron-Daniel, & Moss, 2015; Muftin & Thompson, 2013; Norman & Moss, 2015). Since these reviews reflect only published and grey literatures, we also sought evidence of the support provided by psychosocial specialists working with patients and their families in practice.

Burn care is the only area where some, albeit limited, information exists. In 2001, a survey of staff providing psychological services to burns patients in 25 European countries was compared with data from the US, and found greater provision of support in the US than in Europe (Van Loey, Faber, & Taal, 2001). No significant differences were found between European countries. Half the European hospitals surveyed provided psychological services to less than 20% of burn inpatients, and less than 30% formally tested patients to identify those warranting support. Burn centres in Europe are now required to have a psychologist and social worker readily available (European Burns Association, 2017). A survey of 166 members of burn care teams in the US and UK (Lawrence, Qadri, Cadogan, & Harcourt, 2016) found UK teams were more likely to include psychologists, whereas social workers were more common in the US. Screening for distress was more common in the UK. CBT was the approach most commonly used by those identifying themselves as mental health practitioners, followed by acceptance and commitment therapy (ACT) or mindfulness.

While these surveys highlight support for people with burns, little is known about the provision for those with other conditions. To address this knowledge gap, we designed and conducted a survey to provide a holistic pan-European snapshot of current specialist support for people with visible differences, which could inform future research and clinical work. Specifically, we aimed to establish: (a) who provides specialist psychosocial support, in what context, and how is it accessed?; (b) how are clients' needs identified?; and (c) what interventions and approaches are currently being used? We also sought views regarding how care and research could be developed.

2. Method

The first author's institution granted ethics approval. The survey was created by members of the Clinical Interventions workgroup of the Appearance Matters COST Action (see above), informed by surveys in burn care (see Lawrence et al., 2016). The draft survey was amended following feedback from two clinicians, independent of the task group. Most questions were 'closed', with some open questions allowing respondents to expand on previous answers. At the outset, the group agreed that the target sample were likely to have a good understanding of English since their training and subsequent clinical work would involve academic papers and meetings conducted in English. Consequently, the survey was produced in English, but later translated into German and Portuguese in an attempt to increase responses. It was open to all psychosocial specialists in Europe self-identifying as working with clients with visible differences. Given the lack of any single over-arching European-wide organisation representing these specialists, our recruitment strategy was pragmatic, using snowballing to gather a large sample from as many countries as possible. The link to an online survey was disseminated via social media, and emails from the authors to relevant professional bodies (e.g., British Burn Association) and support organisations (e.g., European Cleft Organisation) who distributed it to their membership through emails and newsletters. It was also sent to the broader membership of the COST Action and the authors' own local and national contacts. Quantitative data was subjected to descriptive statistical analysis (SPSS for Windows, v20), and qualitative data to content analysis.

3. Results

The mean age of respondents ($N = 116$) was 42.5 years ($SD = 11.7$) and most were females ($n = 102$; 87.9%). Almost half were from the UK ($n = 53$, 45.7%), with others from the Netherlands ($n = 21$), Spain ($n = 6$), Norway ($n = 6$), Switzerland ($n = 6$), Austria ($n = 4$), Denmark ($n = 3$), Italy ($n = 3$), Ireland ($n = 2$), Portugal ($n = 2$), and one participant each from Belgium, Sweden, Bulgaria, Greece, and Poland. Five did not specify a country.

3.1. Who provides specialist psychosocial support, in what context, and how is it accessed?

Most respondents were qualified ($n = 73$, 62.9%) or trainee ($n = 6$; 5.2%) clinical psychologists. Others identified as health psychologists ($n = 5$; 4.3%), psychotherapists ($n = 13$; 11.2%), counsellors ($n = 11$; 9.7%), nurse specialists ($n = 7$; 6%), social workers ($n = 7$; 6%) or 'other' ($n = 8$; 6.9%). They worked across numerous specialties, mostly cleft lip/palate ($n = 36$; 31%), cancer ($n = 32$; 27.6%), and burns ($n = 29$; 25%). Some worked in multiple specialities, and most in more than one location, including hospital inpatient ($n = 76$; 65.5%) or outpatient ($n = 85$; 73.3%) settings funded by the state.

Most were part of a multidisciplinary team ($n = 103$; 88.8%). Many ($n = 43$; 36.5%) were the only psychosocial specialist in their team, whilst others worked with one ($n = 18$; 15.7%) or two ($n = 26$; 22.6%) others. Referrals came from specialist multidisciplinary teams (a reported mean of 39.7% of all referrals received), other specialties in general hospital/secondary care settings ($M = 24.7\%$), self-referral ($M = 15.8\%$), other sources ($M = 11.3\%$), and primary care/family doctors ($M = 10\%$).

3.2. How are clients' needs identified?

Almost one-third of respondents ($n = 35$; 31.3%) reported a structured approach towards psychological screening in their service (e.g., routinely using standardised questionnaires). Slightly fewer reported informal screening such as speaking to patients without using structured interviews ($n = 27$; 24.1%), or no routine screening ($n = 33$; 29.5%).

3.3. What interventions and approaches are used?

Respondents often worked with more than one age group (see Table 1), which explains why the total N (164) for this section is greater than the sample size. The most common reasons for referral across all age groups were: low self-esteem/confidence (reported by 137; 83.5%); body image/appearance concerns ($n = 134$; 81.7%); social anxiety/avoidance ($n = 125$; 76.2%); teasing, bullying, or staring ($n = 119$; 72.6%); and depression/low mood ($n = 119$; 72.6%).

More than half considered access to psychosocial support was easy in both inpatient (60%) and outpatient settings (56.7%); the remainder thought patients had difficulty accessing support in these settings. Various approaches and techniques were used (see Table 2), most frequently CBT ($n = 70$; 60.3%), psycho-education ($n = 60$; 51.7%), and mindfulness ($n = 47$; 40.5%).

Few participants used online or remote interventions ($n = 14$; 15.2%), the majority of which used telephone-based counselling ($n = 11$; 78.6%). Whilst the majority referred patients on to support elsewhere ($n = 71$; 77.2%), 10 of the 15 respondents who provided a reason for not referring on indicated suitable services were not available.

3.4. How do psychosocial specialists think care and research could be developed?

Only 48 respondents (38%) felt they had received sufficient training around interventions for people with a visible difference.

Table 1
Respondents' reported reasons for referral to them for intervention/support.

	Client Group			
Reason	Children (*n* = 60) *n* (%)	Adolescents (*n* = 58) *n* (%)	Adults (*n* = 46) *n* (%)	Total (*n* = 164) *n* (%)
Low self-esteem/confidence	47 (78.3)	53 (91.4)	37 (80.4)	137 (83.5)
Body image/appearance concerns	45 (75.0)	48 (82.8)	41 (89.1)	134 (81.7)
Social anxiety/avoidance	43 (71.7)	48 (82.8)	34 (73.9)	125 (76.2)
Experiencing or worrying about teasing, bullying, or staring	45 (75.0)	46 (79.3)	28 (60.8)	119 (72.6)
Depression/low mood	31 (51.7)	46 (79.3)	42 (91.3)	119 (72.6)
Coping with comments or questions	42 (70.0)	42 (72.4)	24 (52.2)	108 (65.9)
Treatment decision making	34 (56.7)	34 (56.7)	25 (54.3)	93 (56.7)
Preoccupied/worried about scars	30 (50.0)	37 (61.7)	24 (52.1)	91 (55.5)
Withdrawal	32 (53.3)	31 (53.4)	22 (47.8)	85 (51.8)
Post-traumatic stress	22 (36.7)	24 (41.4)	28 (60.8)	74 (45.1)
Procedural anxiety	32 (53.3)	27 (56.3)	11 (23.9)	70 (42.6)
Shame	20 (33.3)	22 (36.7)	26 (56.5)	68 (41.5)
Behavioural problems	34 (56.7)	21 (36.2)	10 (21.7)	65 (39.6)
Routine referrals as part of the patient pathway	27 (45.0)	22 (36.7)	15 (32.6)	64 (39.0)
Relationship/romantic/sexuality issues	na	30 (51.7)	30 (65.2)	60 (57.7)
Refusing treatment/difficulties during treatment	26 (43.3)	14 (24.1)	10 (21.7)	50 (30.5)
General anxiety	na	24 (41.4)	23 (50)	47 (43.9)
Sleep problems	18 (30.0)	10 (17.2)	16 (34.8)	44 (26.8)
Preparing for transition/managing own health	na	25 (43.1)	16 (34.8)	41 (39.4)
Pain management	14 (23.3)	11 (19.0)	15 (32.6)	40 (24.4)
Self-injury/harm	8 (13.3)	12 (20.7)	17 (40.0)	37 (22.6)
Guilt	7 (11.7)	9 (15.5)	19 (41.3)	35 (21.3)
Developmental problems	16 (26.7)	10 (17.2)	4 (8.7)	30 (18.3)
Eating disorders/disordered eating	6 (1.0)	10 (17.2)	6 (13.0)	22 (13.3)
Speech/language problems	14 (23.3)	9 (15.5)	2 (4.3)	25 (15.2)
Concerns about neuropsychological functioning	12 (20.0)	9 (15.5)	5 (10.9)	26 (15.9)
Education and learning	13 (21.7)	10 (17.2)	3 (6.5)	26 (15.9)
Family problems	23 (38.3)	na	na	23 (38.3)
Genetic/inheritability of a condition	8 (13.3)	6 (10.3)	6 (13.0)	20 (12.2)
Attachment issues/parent-child relationships	20 (33.3)	na	na	20 (33.3)
School transition	30 (50.0)	na	na	30 (50.0)
Risky behaviours (e.g., abuse of alcohol)	na	8 (13.8)	11 (23.9)	19 (18.3)
Feeding/eating/drinking	11 (18.3)	na	na	11 (18.3)
Other	6 (10.0)	3 (5.2)	4 (8.7)	13 (7.9)

Note. Total *N* (164) for this section is greater than the sample size (116) because some respondents worked with more than one age group. na = not asked.

Table 2
Therapeutic approaches and techniques reported by respondents.

Therapeutic Approach	*n (%)*	Therapeutic technique	*n* (%)
Cognitive behavioural therapy (CBT)	70 (60.3)	Self-esteem building	65 (56.0)
Psycho-education	60 (51.7)	Challenging negative thoughts	58 (50.0)
Mindfulness	47 (40.5)	Exploring patients' expectations	58 (50.0)
Solution focussed	42 (36.2)	Goal setting and pacing	58 (50.0)
Acceptance and commitment therapy	38 (32.8)	Relaxation	57 (49.1)
Systemic and family therapy	36 (31.0)	Graded exposure	54 (46.6)
Compassion-focused	29 (25.0)	Behavioural tasks/homework	54 (46.6)
Motivational interviewing	26 (22.4)	Social interactions skills training	53 (45.7)
Narrative based	26 (22.4)	Self-regulation	47 (40.5)
Eye movement desensitisation & reprocessing (EMDR)	18 (15.5)	Role play	44 (37.9)
Positive psychology	17 (14.7)	Distraction	44 (37.9)
Social learning/behaviour therapy	15 (12.9)	Keeping a diary	40 (34.5)
Rogerian/humanistic	13 (11.2)	Metaphors	38 (32.8)
Hypnotherapy	11 (9.5)	Supporting shared decision making	38 (32.8)
Psychodynamic	10 (8.6)	Peer support	35 (30.2)
Gestalt therapy	7 (6.0)	Action planning	28 (24.1)
Classical conditioning	6 (5.2)	Mirror exposure	26 (22.4)
Expressive writing	6 (5.2)	Co-creating narratives	23 (19.8)
Rational emotive behaviour therapy	0 (0)	Eliciting values	22 (19.0)
		Meditation	19 (16.4)
		Attention-bias modification	17 (14.7)
		Hypnosis	9 (7.8)
		Biofeedback	5 (4.3)
		Virtual reality	5 (4.3)
		Medication	3 (2.6)
		Other	14 (12.1)

Ninety free-text responses to the question "How could support be improved in your country?" were independently coded by two researchers/authors (CH, DH). Codes were compared and any disagreements were discussed until consensus was reached, resulting in four themes:

1 Increase awareness of psychosocial issues associated with a visible difference: 30 responses suggested increased awareness amongst health professionals and the wider public would reduce stigma associated with seeking help.

2 Increase access to support: 16 responses referred to addressing barriers, for example via easily accessible online support and materials in different languages.
3 Increase the number of psychosocial specialists trained in appearance-related issues: 20 responses identified a need to improve training opportunities and funding to increase the number of specialists in this field.
4 Standardise psychological care: 24 responses suggested psychosocial needs should be routinely assessed and addressed within the patient pathway.

4. Discussion

We explored the current provision of specialist psychosocial support for people with visible differences across Europe, to understand how care and research could be developed. Our comprehensive survey, the first to take a pan-European perspective, gathered responses from specialists in 15 countries working with adults, adolescents and children in a range of specialties. Most respondents were qualified or trainee clinical psychologists, but several other professions were also represented. Many reported needing more training in order to confidently support patients with psychosocial needs associated with visible difference.

Most respondents' work focussed on building self-esteem and challenging negative thoughts, in response to low self-esteem, body image and appearance concerns, and social anxiety and avoidance. Our findings highlight the dominance of CBT, reflecting the historic trend of delivering and researching CBT interventions generally, and the conclusions of previous systematic reviews (Bessell & Moss, 2007; Jenkinson et al., 2015; Muftin & Thompson, 2013; Norman & Moss, 2015) and a survey (Lawrence et al., 2016) in the field of visible differences. We also identified widespread use of psycho-education and mindfulness-based approaches and techniques. Some respondents reported using alternatives such as EMDR and gestalt therapy, which have received little attention from researchers in this area. This variety may reflect an awareness of the value of an eclectic approach in order to best meet patients'/clients' specific needs, and of equipping individuals with a mixed repertoire of evidence-based approaches and techniques (Rumsey & Harcourt, 2012). There is a strong theoretical rationale for the use of third-wave interventions for people with visible differences (see Zucchelli, Donnelly, Williamson, & Hooper, 2017), although limited empirical research is available. Evaluating the effectiveness of all under-researched approaches in this field should be a priority.

Involvement in the Appearance Matters COST Action made us acutely aware of the dearth/absence of specialist support in many parts of Europe, giving us confidence that we reached the few relevant specialists in some countries. Unfortunately, this precluded statistical comparisons between countries and, whilst responses from 15 countries provide a complex and valuable dataset, we recognise that many countries are not represented. Political and economic circumstances vary considerably across Europe; some countries offer free access to healthcare and support, others do not. It is therefore not surprising that the provision of psychosocial support for visible difference also differs, and may be less available and accessible in some countries than others. Hopefully, these findings will prompt further work to examine reasons for disparity, and to increase availability of support where it is limited or lacking.

Recently, Williamson et al. (2017) surveyed 718 health professionals, 69 of whom worked in appearance-related specialities such as reconstructive surgery. Respondents reported lacking knowledge about the psychosocial impact of visible differences and would welcome training in supporting patients with appearance-related concerns. Our findings support this training need; relevant online materials are now freely available in various languages (see www.appearancetraining.com; www.facevalue.cc; www.whenlooks.eu; www.ihem.no) and warrant promotion and further translation.

We also identified a need to lobby for additional resources/funding in terms of workforce planning, and potential for increased use of online or remote specialist support. Translations of web-based interventions (e.g., www.faceitonline.org.uk; www.ypfaceit.org.uk) are being trialled in Norway and the Netherlands, and could pave the way for further translations and developments in this field. Sharing experiences and resources between psychosocial specialists may be useful, and ways of facilitating such networking should be explored.

Our study has limitations. We could be criticised for not recruiting directly through hospitals/clinics, but it is very likely that specialists working in this field are members of their relevant professional body and recruiting through health services could mean we would not contact those working solely in private practice or for patient support organisations, hence the recruitment strategy we chose to employ. As with any online study using snowballing recruitment techniques, we do not know the number or details of potential participants who received the survey link. We do not, therefore, know if our sample is representative of specialists working in this field across Europe. These issues have been highlighted in similar online European surveys (see Kyriakou et al., 2016). Also, we relied on respondents self-identifying as a relevant specialist. Many worked across multiple patient/client groups and, in order to keep the survey manageable for participants, we did not ask which approaches/techniques they used with each group. Unfortunately, it was not therefore possible to consider results according to condition or age group. However, there is considerable consistency in the issues facing people with visible differences, regardless of the nature of that difference. We believe the lack of analysis according to condition is not a significant issue, although future research could examine this further, for example by focussing on children, or those with craniofacial conditions. Qualitative research could usefully offer a deeper cross-cultural understanding of specialists' experiences of providing support for these groups, not only in Europe but also more globally.

Finally, the survey was originally disseminated in English, and most respondents were from the UK. This could reflect a stronger tendency to involve psychologists within multi-disciplinary teams in the UK (see Lawrence et al., 2016), and/or the existence and resources of UK professional bodies who promoted the survey. Resources are needed to ensure future research includes non-English speaking participants if we are to gain a truly pan-European or global perspective. Yet, despite these limitations, this survey provides a valuable insight into current psychosocial support for people faced with the challenges of a visible difference across Europe.

5. Conclusions

Until now, little has been known about the provision of specialist psychosocial support for people with visible differences. This, the first pan-European survey in this field, highlights current provision, likely disparity in availability, a need to increase access to specialist support, and shines a light on areas for further development of clinical practice. Findings indicate a need for additional training, and areas for research including evaluation of lesser-used psychosocial approaches. We now have a European evidence base which can inform future research, service development, and policy relating to people living with visible differences.

Conflicts of interest

None.

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